



Informed Prostate Cancer Support Group Inc.

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September 2012 NEWSLETTER

P.O. Box 420142 San Diego, CA 92142

Phone: 619-890-8447 Web: www.ipcsg.org

We Meet Every Third Saturday (except December)



Wednesday, September 05, 2012

Volume 5, Issue 8

Officers

President: Lyle La Rosh,
Vice President : Gene Van Vleet

Additional Directors

Dr. Dick Gilbert
John Tassi
George Johnson

Steering Committee

Judge Robert Coates
Victor Reed
Carlos Richardson
Robert Keck, Librarian
Bill Manning
E. Walter Miles
Jerry Steffen
Robert Werve, Treasurer

Next Meeting

September 15th

10:00AM to Noon

**Meeting at
Sanford-Burnham
Auditorium
10905 Road to the
Cure, San Diego CA
92121**

**SEE MAP ON THE
LAST PAGE**

**"Blue" September is
National Prostate
Cancer Awareness
Month**

What We Are About

Our Group offers the complete spectrum of information on prevention and treatment. We provide a forum where you can get all your questions answered in one place by men that have lived through the experience. Prostate cancer is very personal. Our goal is to make you more aware of your options before you begin a treatment that has serious side effects that were not properly explained. Impotence, incontinence, and a high rate of recurrence are very common side effects and may be for life. Men who are newly diagnosed with PC are often overwhelmed by the frightening magnitude of their condition. Networking with our members will help identify what options are best suited for your life style.

Be your own health manager!!

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Editor: Gene Van Vleet

AUGUST 2012 MEETING NOTES

The August meeting was well attended with 102 participating of which 8 were newcomers.

Our guest speaker was Dr. John Grimaldi, Grimaldi Urology. Dr. Grimaldi opened by pointing out that around 30 million men have issues with impotence and incontinence. There is an underserved area of medicine that needs to focus on lifestyle and quality of life. Too often your doctor does not deal with these matters.

Incontinence is the involuntary loss of urine. About 9% of men between the ages of 18 and 97 are experiencing some form of incontinence. 13%

Video DVD's

DVD's of our meetings are available in our library for \$10ea. Refer to the index available in the library. They can also be purchased through our website: <http://ipcsg.org>

Click on the 'Purchase DVD's' button.

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of men over the age of 60 have issues regardless of prostate cancer or other illnesses. There are many forms of incontinence wherein something causes the pressure of the fluid inside the bladder to exceed the pressure of restraining it by the urethral sphincter which is the muscle that keeps the opening closed. BPH, prostate cancer surgery and radiation therapy are among the things that can interfere with the ability of the muscle to function properly. Incontinence is best diagnosed by obtaining history from the patient plus performing a cystoscopy. If the issue is BPH, an enlarged prostate, it most often can be treated with medication. If there is damage due to surgery or something else causing impairment, a sling or an artificial sphincter can be put in place without-patient surgery. The artificial sphincter functions for 5 to 8 years.

When opting for prostate surgery or radiation therapy, Dr. Grimaldi strongly emphasized the importance of a penile rehabilitation program PRIOR to having the treatment.

Erectile dysfunction (ED) is the inability to achieve an erection firm enough to have intercourse. One in ten men worldwide is affected. Fifty percent of men with diabetes have ED. Forty percent of men over the age of 40 and 65% over the age of 65 will experience some form of ED. Smokers are twice as likely to develop ED. All forms of treatment for prostate cancer have a penalty of ED.

Unfortunately, men are reluctant to discuss issues of ED. Medications do work, but you should be analyzed by a knowledgeable doctor that is capable of determining your issues and recommending the appropriate remedy. Dr. Grimaldi is confident that if you want to overcome ED, he can help you achieve it. Often the first thing men do when confronted with ED is nothing. Next they begin to think about or try the heavily marketed products. Sometimes they do work, but often only for a month or two because of the placebo effect. He has the majority of his patients on daily doses of Viagra, Cialis or Levitra because good results are achieved with fewer side effects. Injections do work, but there are issues with convenience of usage and sometimes scarring if used over time. Vacuum tubes are useful but also inconvenient and unromantic. Penile prostheses are a viable solution. Dr. Grimaldi is one of the most proficient in the technique of penile implants.

For more valuable details of Dr. Grimaldi's presentation, including very informative Q&A's, are on DVD available for purchase in the library or through our website: www.ipcsg.org.

In Memorium

Carlos Richardson, longtime principal in the organization of and service to IPCSG passed away last month at the age of 92. He served as Secretary/Treasurer as well as editor of the newsletter and was highly regarded for advocacy of prostate cancer. He survived our disease for over 20 years. Donations in his memory may be made to the Informed Prostate Cancer Support Group.

Future Meetings

September 15. Experience Exchange. A few selected members will talk of their experience after which sub-groups by treatment type will network.

If you have leads to speakers related to the interests of our group please contact:
lyle@ipcs.org or gene@ipsg.org

NOTEWORTHY ARTICLES

LIGHTEN UP!!!!

Subject: MY NEW PRIMARY CARE PHYSICIAN

Love this Doctor!



Q: Doctor, I've heard that cardiovascular exercise can prolong life. Is this true?

A: Heart only good for so many beats, and that it... Don't waste on exercise. Everything wear out eventually. Speeding up heart not make you live longer; it like saying you extend life of car by driving faster. Want to live longer? Take nap.

Q: Should I reduce my alcohol intake?

A: Oh no. Wine made from fruit. Brandy distilled wine, that mean they take water out of fruity bit so you get even more of goodness that way. Beer also made of grain. Bottom up!

Q: How can I calculate my body/fat ratio?

A: Well, if you have body and you have fat, your ratio one to one. If you have two body, your ratio two to one.

Q: What are some of the advantages of participating in a regular exercise program?

A: Can't think of single one, sorry. My philosophy: No pain...good!

Q: Aren't fried foods bad for you?

A: YOU NOT LISTENING! Food fried in vegetable oil. How getting more vegetable be bad?

Q: Will sit-ups help prevent me from getting a little soft around the middle?

A: Oh no! When you exercise muscle, it get bigger. You should only be doing sit-up if you want bigger stomach.

Q: Is chocolate bad for me?

A: You crazy?!? HEL-LO-O!! Cocoa bean! Another vegetable! It best feel-good food around!

Q: Is swimming good for your figure?

A: If swimming good for figure, explain whale to me.

Q: Is getting in shape important for my lifestyle?

A: Hey! 'Round' is shape!

Well... I hope this has cleared up any misconceptions you may have had about food and diets.

And remember:

Life should NOT be a journey to the grave with the intention of arriving safely in an attractive and well-preserved body, but rather to skid in sideways - Chardonnay in one hand - chocolate in the other - body thoroughly used up, totally worn out and screaming "WOO-HOO, what a ride!!"

AND.....

(Continued from page 3)

For those of you who watch what you eat, here's the final word on nutrition and health. It's a relief to know the truth after all those conflicting nutritional studies.

1. The Japanese eat very little fat and suffer fewer heart attacks than Americans.
2. The Mexicans eat a lot of fat and suffer fewer heart attacks than Americans.
3. The Chinese drink very little red wine and suffer fewer heart attacks than Americans.
4. The Italians drink a lot of red wine and suffer fewer heart attacks than Americans...
5. The Germans drink a lot of beer and eat lots of sausages and fats and suffer fewer heart attacks than Americans.

CONCLUSION: Eat and drink what you like. Speaking English is apparently what kills you.

Enzalutamide Gets FDA Nod for Late-Stage Prostate Cancer

Reprinted from Medscape Today posted 8/31/12

August 31, 2012 — The US Food and Drug Administration (FDA) has approved enzalutamide (formerly known as MDV3100) to treat men with metastatic castration-resistant prostate cancer that has spread or recurred.

Developed by Astellas Pharma US Inc and Medivation Inc, the drug will be sold as Xtandi. It was reviewed under the FDA's priority review program, which provides for an expedited 6-month review for drugs that may offer major advances in treatment or that provide a treatment when no adequate therapy exists.

Xtandi, which was approved 3 months sooner than expected, is one of a new class of androgen inhibitors designed to interfere with the ability of testosterone to bind to prostate cancer cells.

According to the National Cancer Institute, an estimated 241,740 men will be diagnosed with prostate cancer and 28,170 will die from the disease in 2012.

"The need for additional treatment options for advanced prostate cancer continues to be important for patients," Richard Pazdur, MD, director of the Office of Hematology and Oncology Products in FDA's Center for Drug Evaluation and Research, said in a statement posted on the FDA Web site.

"Xtandi is the latest treatment for this disease to demonstrate its ability to extend a patient's life," Dr. Pazdur added.

Early End to Pivotal Trial

As reported by Medscape Medical News, in a study of nearly 1200 patients with metastatic castration-resistant prostate cancer previously treated with docetaxel-based chemotherapy, enzalutamide significantly prolonged median survival compared with placebo (18.4 vs 13.6 months; hazard ratio, 0.63; $P < .0001$).

The pivotal phase 3 trial, known as A Study Evaluating the Efficacy of the Investigational Drug MDV3100 (AFFIRM) was stopped early. The results were published online August 15 in the New England Journal of Medicine.

"This is an important new drug," Marc Garnick, MD, clinical professor of medicine at Harvard Medical School, with an oncology practice at Beth Israel Deaconess Medical Center, in Boston, Massachusetts, told Medscape Medical News on publication. "It will add greatly to the treatments that can be offered to our patients with advanced prostate cancer," he added. Dr. Garnick was not involved in the AFFIRM trial.

The FDA notes that the most common adverse effects observed with enzalutamide were "weakness or fatigue, back pain, diarrhea, joint pain, hot flush, tissue swelling, musculoskeletal pain, headache, upper respiratory infections, dizziness, spinal cord compression and cauda equina syndrome, muscular weakness, difficulty sleeping, lower respiratory infections, blood in urine, tingling sensation, anxiety, and high blood pressure."

In addition, seizures occurred in approximately 1% of those receiving enzalutamide. These patients stopped the drug. Patients with a history of seizure were excluded from the study, as were patients with an underlying brain injury with loss of consciousness, a temporary decrease in blood to the brain within the past 12 months, stroke, brain metastases, an abnormal connection of the arteries and veins in the brain, or patients taking medications that may lower the seizure threshold. "The safety of Xtandi is unknown in patients with these conditions," the FDA says

Managing Too Much Information—The PCRI's Approach

Posted: 28 Aug 2012 06:00 AM PDT from Prostate Snatchers Blog

BY MARK SCHOLZ, MD

Knowledge is power. And what you don't know can indeed hurt you. However, in this modern information age, the deluge of unfiltered data can be completely overwhelming. How can patients without professional training sort it all out and distil for themselves a sensible plan of action?

No one can offer a quick fix. Prostate cancer is too complex and there are too many behind-the-scene conflicts-of-interest simply to trust the first smiling doctor you encounter. Although you can't escape from the responsibility of doing your homework, you had better make sure you're in the right classroom.

Because prostate cancer is so varied in how it affects men, PCRI has divided the disease into five major categories, which we have called Shades of Blue. This division emphasizes the extreme diversity of this infirmity we call prostate cancer, a condition that ranges from totally innocuous to fatal.

In the process of learning about prostate cancer, failing to stick to the domain of a single Shade is like wandering randomly between five classrooms that are teaching five different subjects. Is it any wonder there is so much confusion? Patients don't need more information. They need unbiased information that is tailored to their specific needs, i.e. their Shade of prostate cancer.

When you think about it, it's obvious why we need a new approach to information management. In the old days, new discoveries came slowly. The doctors who were thought leaders had plenty of time to attend medical conferences to discuss disease management in a leisurely fashion to achieve broad consensus. Those days are gone forever. In this era of rapidly changing technology, consensus about a treatment probably means the treatment is out of date. These days, new treatments are vetted by experts on prime-time news. Unfortunately, breaking news, due to its fundamental need to be controversial and attract an audience, tends to emphasize fringe thinking.

Relying on traditional university centers to define a sensible, middle-of-the-road plan of action is also no longer possible. Prostate cancer is big business and most large treatment centers specialize in one form of therapy such as radiation or surgery to the exclusion of all the others. Studies show that large specialty centers do indeed yield better quality than centers treating fewer numbers of patients. However, the large centers are understandably biased toward recommending their specific form of therapy. Their advice about which treatment to select is all too often tainted by their financial conflict of interest.

The PCRI's mission is to fill the cavernous need for unbiased information that has been created by the accelerated rate of technological discovery. Rapidly exploding technology and new treatments are a great blessing as long as these powerful tools are applied selectively and appropriately to individuals who can benefit, while withholding potentially toxic treatments from those who won't benefit or may actually be done some harm.

With the annual PCRI conference rapidly approaching, PCRI will continue striving to fulfill its mission to provide up-to-date and scientifically-based information that helps patients and their families sort through the ever expanding number of treatment options.

Announcements

NETWORKING

The original and most valuable activity of the INFORMED PROSTATE CANCER SUPPORT GROUP is “networking”. We share our experiences and information about prevention and treatment. We offer our support to men recently diagnosed as well as survivors at any stage. Networking with others for the good of all. Many aspects of prostate cancer are complex and confusing. But by sharing our knowledge and experiences we learn the best means of prevention as well as the latest treatments for survival of this disease. So bring your concerns and join us.

Please help us in our outreach efforts. Our speakers bureau consisting of Lyle LaRosh, Gene Van Vleet and George Johnson are available to speak to organizations of which you might be a member. Contact Gene 619-890-8447 or gene@ipcsg.org to coordinate.

Member and Director, John Tassi continues to develop our new website that we believe is simple and easy to navigate. **Check out the Personal Experiences page and send us your story.** Go to: <http://www.ipcsg.org>

Our brochure provides the group philosophy and explains our goals. Copies may be obtained at our meetings. Please pass them along to friends and contacts.

Ads about our Group are in the Union Tribune 2 times prior to a meeting. Watch for them.

Our Steering Committee meets for lunch, usually at Baci's restaurant (preferred) at noon on the first Tuesday of each month. All members are welcome! Please call Lyle La Rosh at 619-892-3888, to make reservations and to verify location.

Library Announcement "To all those who have borrowed books, tapes or DVD's please return them at the next meeting"

We Need Help

All services for our group are performed by volunteers. As is usual in our type of organization we have a few doing a lot for many. We need people to step up and help in the following areas:

1. Fund Raising. We need help from anyone with any knowledge or willingness to become involved in acquiring grants to support our organization. We need someone to organize fund raising activities.
2. Information Technology. Any techies out there that can help take advantage of the facilities available where we meet--such as live remote conferencing.

Anyone interested please contact:

Gene Van Vleet, Vice President. 619-890-8447 gene@ipcsg.org

Lyle LaRosh, President 619-892-3888 lyle@ipcsg.org

HEALTH INSURANCE NEWS

Affordable Care Act gives consumers new tools, makes health insurance market more transparent

Created under the Affordable Care Act, www.HealthCare.gov was launched July 1, 2010, and is the first website of its kind to bring information and links to health insurance plans into one place to make it easy for consumers to learn about and compare their insurance choices. HHS' Office of Consumer Information and Insurance Oversight (OCIO) worked to define and collect detailed benefits and premium rating information from insurers across the country, and starting October 1, 2010, consumers will also be able to find information about health insurance options such as: Monthly premium estimates; Cost-sharing information, including annual deductibles and out-of-pocket limits; Major categories of services covered; Consumer's share of cost for these services; Percent of people in the plan who pay more than the base premium estimate due to their health status; Percent of people denied coverage from a health plan.

More than 225 insurance companies have provided information about their individual and family plans for more than 4,400 policies, including policies in every state and the District of Columbia. Consumers can search for and compare information on plans available based on age, gender, family size, tobacco use and location.

NOTE

California law requires that you have an annual 30-day period beginning on your birthday during which you may purchase any Medicare supplement coverage that offers benefits equal to or lesser than, those of your current coverage. You are eligible to purchase such plans without regard to your health status, claims experience, receipt of health care or medical condition. This only applies if you currently are on Medicare.

Mr. David Weil from Health Insurance Counseling and Advocacy Program (HICAP) provided information about their free services in our October, 2011 meeting. HICAP is a non-profit program that assists with counseling about medicare coverage and billing issues, including appeals. They do not make recommendations but rather provide information to help individuals make decisions about available coverage. They also assist with Long Term Care Insurance. The local phone number is 858-565-8772 or, if calling from a cell phone outside of the San Diego Area, 800-434-0222. Website: <http://www.cahealthadvocates.org/HICAP/sandiego.html>

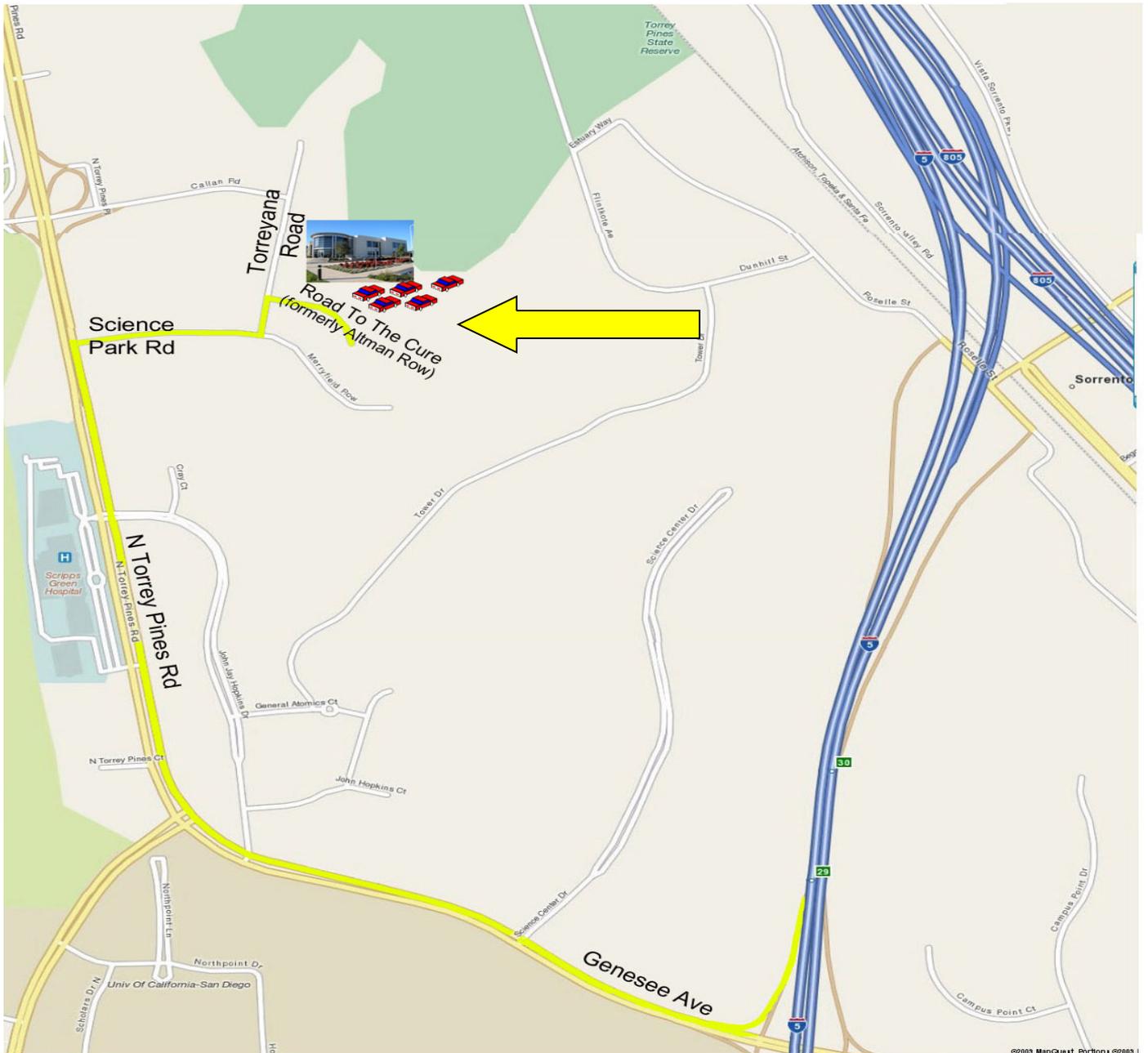
If you have particular knowledge that would be helpful to our goal of creating a base of information, please volunteer your efforts to the committee. Contact Gene Van Vleet, e-mail gene@ipcsg.org or cell phone 619-890-8447 who may redirect your inquiry to an appropriate person for response.

FINANCES

We want to thank those of you who have made special donations to IPCSG. Remember that your gifts are tax deductible because we are a 501(c)(3) non-profit organization.

We again are reminding our members and friends to consider giving a large financial contribution to the IPCSG. This can include estate giving as well as giving in memory of a loved one. You can also have a distribution from your IRA made to our account. We need your support. We will, in turn, make contributions from our group to Prostate Cancer researchers and other groups as appropriate for a non-profit organization. Our group ID number is 54-2141691. Corporate donors are welcome!

If you have the internet you can contribute easily by going to our website, <http://ipcsg.org> and clicking on "Donate" Follow the instructions on that page. OR just mail a check to: IPCSG, P. O. Box 4201042,



**Directions to Sanford-Burnham Auditorium
10905 Road to the Cure, San Diego, CA 92121**

- Take I-5 (north or south) to the Genesee exit (west).
- Follow Genesee up the hill, staying right.
- Genesee rounds right onto North Torrey Pines Road.
- Do not turn into the Sanford-Burnham Medical Institute or Fishman Auditorium**
- Turn right on Science Park Road.
- Turn Left on Torreyana Road.
- Turn Right on Road to the Cure (formerly Altman Row).